

# Cognitive Disabilities

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According to the American Association for Mental Retardation, an adult is considered to have a cognitive disability based on three criteria. One criterion is intellectual functioning (IQ) that tests at 70–75 or below. However, IQ alone does not determine the level at which someone functions. Two other factors must be present before a person is considered to have a cognitive disability. They must have significant limitations in two or more adaptive skills areas, such as daily living skills, communication, self-care, social skills, academic skills, and work skills, and the condition must be present from childhood. It is estimated that 20 percent of people with developmental disabilities also have epilepsy.

People who are cognitively delayed may need one of four types of support, ranging from intermittent to limited to extensive to pervasive. Intermittent support might involve helping a person find a new job. Limited support might occur during a time of transition, such as on-the-job training when someone leaves school. Extensive support involves a need on a daily basis throughout the individual's lifetime but may occur just at home or just at work. Pervasive support involves all life areas and may involve life-sustaining activities throughout the individual's lifetime.

For the purpose of this book, the term *cognitive disability* is used to describe individuals who have a disability that limits their ability to learn and reason because it is the term used by DPI. Other terms that one finds include *mentally retarded*, *intellectually disabled*, and *developmentally delayed*. *Mentally retarded* is used somewhat less frequently within the Wisconsin school systems; however, several national service agencies continue to use this term, as do several federal educational agencies. *Developmentally delayed* includes individuals who have cognitive disabilities but also includes many people who have normal intelligence but have a delay in their physical or cognitive development. *Intellectually disabled* is a term preferred by some agencies.

## Causes of Cognitive Disabilities

The cause of cognitive disabilities is known for about two-thirds of the cases. Damage can occur before or during birth or in the early childhood years. Common causes include the following:

- Fetal alcohol syndrome
- Down syndrome
- Fragile X syndrome
- Autism

Genetic conditions such as the abnormality or mutation of an inherited gene or genetic damage caused by infections or X rays can all result in cognitive disabilities. Linda Lucas Walling and M. M. Irwin state in *Information Services for People with Developmental Disabilities* (Walling and Irwin 1995) that some researchers consider fetal alcohol syndrome to be the most frequent cause of cognitive disabilities in the Western world. Use of alcohol or drugs by the mother often causes these types of disabilities. Smoking by the mother is associated with a higher risk of these intellectual disabilities. Other factors include malnutrition, environmental toxins, and certain illnesses of the mother while pregnant, such as rubella or syphilis. Prematurity and low birth weight are both associated with cognitive problems.

The following are the known major causes of cognitive disabilities. Childhood diseases such as whooping cough, chicken pox, measles, and Hib disease (one of any bacterial infections such as pneumonia, epiglottitis, or pericarditis) can lead to meningitis and encephalitis, which often damage the brain. Accidents that result in head damage, near drowning, and lead (from paint or water) or mercury poisoning are also known causes of cognitive disabilities. Poverty is associated with cognitive disabilities because of the high incidence of malnutrition, conditions that produce disease, inadequate access to medical care, and increased exposure to health hazards in the home environment.

Medical advances have addressed several problems that resulted in cognitive disability in the past. Newborn screening can identify PKU (phenylketonuria), Rh disease, jaundice, and hypothyroidism before damage occurs and when it is treatable. Vaccines can prevent Hib diseases, measles, and rubella. Lead is no longer used in water pipes or in paint, which reduces incidents of cognitive disabilities caused by lead poisoning. Car seats and bike helmets reduce the incident of head trauma. Good prenatal care for mothers and dietary supplements that include folic acid help reduce the risk of damage to neural tubes that result in spina bifida and anencephaly, a condition in which the baby's brain fails to develop. Reye's syndrome is now more readily recognized, and parents are discouraged from using aspirin-based products to treat a fever. The question of a relationship between vaccines and autism continues to be debated and is currently being investigated by researchers, including those at the University of Wisconsin-Madison Waisman Center.

## Demographics

According to The Arc (2002), a national advocacy agency for people with cognitive disabilities and their families, 2.5 to 3 percent of the population (6.2 to 7.5 million people) are thought to have a cognitive disability in the United States. It affects 25 times more people than blindness. About 85 percent of people with cognitive disabilities are mildly affected and will only be a little slower than average in learning new information and skills. The remaining 15 percent have IQ scores under 50 and have serious limitations on their functioning.

The Wisconsin Council on Developmental Disabilities' Web page ([www.wcdd.org](http://www.wcdd.org)) indicates that the prevalence rate they use is 1.8 percent. This count refers to people with developmental disabilities who receive public funding and would not include people who have borderline disabilities but lead independent lives. It is important to understand that developmental disabilities include people who have disabilities such as cerebral palsy and autism, but who have normal intelligence, as well as people who have cognitive disabilities. However, the majority of people with developmental disabilities have a cognitive disability. The council estimates that approximately 10,000 children between birth and 3 years old have development disabilities; 30,000 children between the ages of 3 and 18 have these types of disabilities; and 60,000 adults have them. The *1999–2001 Biennial Report* of the Wisconsin Department of Health and Family Services (2001) indicates that counties provide supported employment services for 4,300 adults with developmental disabilities, the majority of whom can be assumed to have cognitive disabilities.

The Department of Public Instruction maintains a statewide child count of students enrolled in public school special education classes. As of December 1, 2001, there were approximately 13,166 students with cognitive disabilities as their primary disability enrolled in schools in Wisconsin. Although some children with severe cognitive disabilities or children with multiple, profound disabilities live in institutions, the trend is for children to live in their own homes or communities.

Two large organizations provide supervised housing and training for adults with cognitive disabilities. St. Coletta's School in Jefferson serves approximately 390 adult clients, and Bethesda Lutheran Homes and Services headquartered in Watertown serves approximately 280 people. Bethesda owns group homes in Brown Deer, Fort Atkinson, Fox Lake, Hebron, Greenfield, Watertown, Wauwatosa, and West Allis. All are licensed by the state of Wisconsin as community-based residential facilities (CBRFs). Supervised apartment living is available in Fond du Lac and Wauwatosa. Similar services will soon be offered in Fox Lake.

## Related Issues

The support systems for cognitive disabilities and the general aging population are not designed to meet the needs of older adults who have cognitive disabilities. The Arc stresses that aging people with cognitive disabilities should be included in community events and services and be given the same dignity and respect as that offered to other seniors in the community. They should be allowed to live, learn, work, and retire where they like and receive the same financial supports as other older Americans. They should not be discriminated against in terms of housing, health care, aging services, transportation, or library services. This philosophy is echoed by the Wisconsin Bureau of Developmental Disabilities Services on its Web page ([www.dhfs.state.us.bdds](http://www.dhfs.state.us.bdds)): “The common goal is inclusion; that is people living, working, learning, and playing in communities of their choice.” Walling and Irwin (1995) describe seniors with cognitive disabilities as being in “double jeopardy.” This is the result of combining age, which has its own stigma, with the often-devalued status of people with cognitive disabilities.

The Arc’s Web site ([www.thearc.org](http://www.thearc.org)) includes a section devoted to minority groups with cognitive disabilities. Citing a U.S. Office for Civil Rights survey (1986–87), it reports that 41.5 percent of the children who are in special education classes because of a cognitive disability belonged to a minority group. This reflects a disproportionate prevalence of cognitive and developmental disabilities within minority groups. In 1990 the Centers for Disease Control conducted a study in Metropolitan Atlanta and found that African American children were four times as likely as Anglo-American children to be classified as having a cognitive disability.

The high incidence and placement of minority children may be explained in part by the cultural bias in IQ tests. Another factor is the higher poverty rate for minorities. Poverty is highly associated with cognitive disabilities because of such factors as poor access to health care, poor maternal nutrition and prenatal care, low birth weights, smoking, drinking, and drug abuse.

People with cognitive disabilities are extremely vulnerable to sexual abuse. They may not understand what is happening during an assault, may not be able to choose to stop it, may not act out of fear, and frequently, may have a dependent relationship with the abuser. More than 90 percent of all people with cognitive disabilities will be the victim of a sexual abuse or assault, many before they are 18 years old.

## Results of the Survey of Library Services to Adults with Special Needs

### Special Needs Survey Questions on Cognitive Disabilities

Question	Number of Libraries Responding Yes	Percentage
• Library has added materials in past three years in the area of cognitive disabilities.	138	47%
• Library staff attended training in the past three years on services to people who have cognitive disabilities.	39	13%
• Library Web page has links to information about cognitive disabilities.	21	7%
• Library has at least one periodical or newsletter intended for people with cognitive disabilities.	11	4%
• In the past three years, the library has had a planning process that included people with cognitive disabilities or their family members or agency advocates.	12	4%

*Note:* In 2002, 293 of Wisconsin’s 380 public libraries completed this survey, a 77 percent response rate. See chapter 12 for the complete survey and a summary of the results.

## Barriers to Service

Interviews of social service agency personnel and other individuals indicate that transportation is a frequent barrier for people with cognitive disabilities. Often, the clients cannot drive, and some cannot easily use public transportation. One interviewee mentioned that there is often a shortage of staff people at group homes or institutions to take groups or individuals into the community.

The nonsocial behavior of some people with cognitive disabilities can often be a barrier to their being in a library. Many people with cognitive disabilities cannot read, or do not read very well, and this may result in the misconception that a public library does not have any resources they can use.

## Planning and Collaboration

Planning for libraries can often include individuals with cognitive disabilities because many function at a fairly high level. They have preferences and can articulate them, and they can give insight into the problems they have in using a library. It may also be good to include parents and caregivers for adults and children who have cognitive disabilities. Public schools provide instruction in most cases through the age of 21. In addition, most local communities have agencies that work with this population. Specific agencies that may be able to provide planning assistance include ARC Wisconsin, Autism Society of Wisconsin, local chapters of United Cerebral Palsy, the Epilepsy Foundation, and the Brain Injury Association of Wisconsin.

### Volunteer Group in Green Lake

The Caestecker Public Library in Green Lake has involved a volunteer group of cognitively disabled adults for about seven years; they remove the date-due stickers from returned items. A group of five to six people comes once a week from the Fox River Industries in Berlin. Director Tasha Saeker notes, “Occasionally, someone has difficulty with the quiet atmosphere at the library, but beyond that they have been absolutely wonderful. In fact, they are our easiest group of volunteers to work with and one that I look forward to seeing every week. I think the key is the wonderful agency staff.”

Interviews indicated that collaboration is critical for getting information about library services to this population and also for arranging transportation.

Collaborating agencies can include the following:

- Local high school special education classes
- Social service agencies
- Employers that provide “sheltered” or supervised work placements
- Agencies that make employment and housing placements for adults with cognitive disabilities
- Adult activity centers that care for adults with cognitive disabilities during the day
- Housing for adults who have cognitive disabilities
- Large private training facilities that may address the needs of many adults with cognitive disabilities
- United Cerebral Palsy, located in numerous Wisconsin communities
- The Arc, which has numerous regional chapters in Wisconsin
- Local councils on developmental disabilities
- Disabilities boards
- Goodwill Industries
- Centers for independence
- Community-based rehabilitation programs

## DeForest Public Library Trains High School Students with Cognitive Disabilities

The DeForest Public Library has a long-standing cooperative training program with the local school district for high school students with cognitive disabilities. The library offers parent packets for reading readiness and to promote science and math activities for families in the community. Several hundred of these packets are given away each month.

The students in the cognitive disabilities class at the high school come to the library on a regular basis to prepare the packets. Their teachers and aides set up an assembly line operation, and the students participate to the degree that they are able. Some students who can function at a higher level may be assigned other library-related tasks such as simple shelving.

The library ends up with the packets it needs prepared for them, and the students gain job skills. Some of the participants who never used the library before become library users because their work at the library makes them comfortable and they see things that interest them while they are working there.

## Staff Training

People with cognitive disabilities may have extremely limited contact with other people. Library staff can become part of their small network of acquaintances. These patrons may appreciate being greeted by name and having materials that match their interests set aside for them. Walling and Irwin (1995) point out that for many people with cognitive disabilities, the social interaction is more important than the activity itself. They note that public libraries can play a significant role in enhancing the quality of life for adults with cognitive disabilities. The collection and service options offered at a public library can be used by the individuals, their family members, and the professionals who work with them.

Adults with cognitive disabilities should be afforded courtesy and respect when they ask questions or need assistance. Rules and limits may have to be explained frequently and be consistently enforced to help them adjust their behavior to the public library environment. Flexibility and understanding in regard to behaviors that may be distracting but unintentional, or not within their ability to control, may be needed. But in general, the behavior of people with cognitive disabilities should be guided by the library's policy on behavior for all patrons.

Interviews indicated that professionals working with people who have cognitive disabilities feel that librarians in general require more training on interacting with this group of patrons. More than one interviewee stressed the need for inclusion in regular library services, rather than special services offered only for people who have cognitive disabilities. Library staff can appreciate that their interactions with people with cognitive disabilities can serve as a model for other people in the community in terms of treating them respectfully, being patient, and allowing them to make decisions. The primary need is to treat adults with cognitive disabilities the same as other adult patrons whenever possible.

The *Guidelines for Library Services to People with Mental Retardation* (American Library Association, Association of Specialized and Cooperative Library Agencies 1999) suggests that staff be trained to recognize that some people cannot control their own behavior. Their behavior may appear unusual, which may frighten both staff and other patrons. Staff training and some tolerance may be required. Adults with cognitive disabilities may require extra time and guidance to make a decision and in using library services. They may need assistance in getting information from the library's catalog and locating materials on the shelf.

Many people who have cognitive disabilities often have other types of disabilities as well, such as mobility, vision, or hearing problems. Personal adaptive equipment for people who have cognitive disabilities

often involves communication technology, which could be a simple speech board with pictures or an electronic voice used with a computer. Because memory is often a problem for people with cognitive disabilities, they may use a visual activity list to get through the day. Library staff need training in working with adaptive devices, especially those for speech, in addition to understanding the general characteristics and behaviors of people with cognitive disabilities.

Friendships, safe environments, and public places where they are accepted are all important to people with cognitive disabilities. The public library may be one of the few public facilities where adults with cognitive disabilities are welcome to spend leisure time. This is important for the individual who likes to come to the library independently, as well as for those who come to the library as part of an outing for their housing unit or day activity center. They often have a great deal of leisure time and need outlets to pursue their interests. Unfortunately, outlets and choices for adults with cognitive disabilities can be extremely limited.

## Collections and Services

The library can have information on the prevention and treatments of cognitive disabilities for the parents, families, and professionals who work with people who have these disabilities. Families need different types of information to address their concerns at different stages of their children's lives and into their adulthood.

Among the suggestions made by the interviewees for materials and services are that public libraries should own and use TTYs (text telephones) and have large-print collections, high-interest, low-vocabulary books, books on tape, and more materials that reflect cultural diversity. One interviewee mentioned that picture directories are very helpful for people with cognitive disabilities. Another indicated that adults with low reading levels do not like to ask for assistance in locating materials they can read, so it is helpful if high-interest, low-vocabulary materials can be shelved in a single location.

Flexibility is the key to providing excellent services to adults with cognitive disabilities when they come to programs or visit the library as part of a group activity. The current philosophy by professionals in the field is that adults with cognitive disabilities should be treated as adults rather than as children. Libraries should try to adapt programs for adults and those planned for all ages to accommodate adults with cognitive disabilities, rather than trying to adjust story programs that are primarily intended to meet the interests and needs of children.

### Outreach Services in West Bend

For several years, Suzanne Curasi, the outreach specialist at the West Bend Community Memorial Library in West Bend, has been reading stories about five times each month for cognitively disabled older adults, in cooperation with an organization called the Threshold (similar to Goodwill). The clients spent most of their developmental years in institutional settings and have functioning levels between 18 months and 6 years of age. Many do not have verbal communication skills. There are weekly reading hours at the library, and the librarian goes to Threshold once a month for those clients whose physical disabilities make it difficult to travel.

The family members or staff who accompany the adults with cognitive disabilities to the library are perhaps in the best position to guide their loved one or clients to appropriate materials of interest to them. Individuals and groups of adults with cognitive disabilities should not be routinely routed to the youth services department, with the assumption that the materials there are the most appropriate. As true for many other adults, there are materials in both departments that may be of interest and use to them. But as with most adults, the majority of the materials that would be of interest are likely to be in the adult department.



## **Adults with Cognitive Disabilities Visit the Jefferson Public Library Regularly**

Staff at the Jefferson Public Library are familiar with services to adults with cognitive disabilities. St. Coletta's School is located just outside the city and provides services to many clients who live independently in the community. Numerous individuals who have cognitive disabilities visit the Jefferson library on a regular basis and are quite independent. Often, these adults function at a very high level, can read, and usually use the library without much assistance.

Small groups of adults with cognitive disabilities also visit the library on a regular schedule, perhaps once a week, with an attendant. These clients often can read and enjoy working with the computers. The library staff work with the attendants and agencies on any problems that arise with the group visits. The individuals in these groups are treated as any other patrons. They are expected to follow the same rules as everyone else. In fact, part of the reason these clients are brought to the library is to help them learn and practice social rules.

In general the visits pose few problems. The library staff try to remain flexible when behavior is not acceptable, and they act as a go-between for the other patrons and the visiting group. Although many of the clients know how to access the Internet, they may request frequent assistance on how to navigate a particular site. This demand for individual instruction and attention cannot always be met because other patrons are using the library at the same time.

Some people in the group are more interested in attention than in actual information. They ask for repeated assistance, more to keep the librarian at their side than from having a real interest in the sites they are visiting. They may make continual reference requests to help find a site and once there immediately request something else without even looking at the site. Limits on the number of requests, or an expectation that the patron will work on a requested site for a certain amount of time before requesting further assistance, may be necessary. These are the types of problem solving the librarians do with the attendants and the agencies involved in bringing groups of clients to the library.

Library staff can be most helpful for groups that come at regular times, such as by pulling adult books that nonreading patrons might enjoy. They can place tactile items, such as globes, raised dioramas, and biology models, where the group can easily see them. They can offer to get the group started with computer programs. Staff can put out a selection of music compact discs (CDs) and offer assistance at listening stations, or they could offer a selection of videos or CD-ROMs and get the program started for those interested in watching it on a viewer or computer. Typically, these services would be offered by staff in the department in which the items are located.

One parent of an adult daughter with cognitive disabilities suggested that adult programs be planned to accommodate people with these types of disabilities. The program presenter could be given some general training in advance. The library can make arrangements to have a helper for the person with the cognitive disability. Although such volunteers might be available through a support agency, and group homes might bring their own staff to assist, it is better to anticipate a cost for this service, just as there are costs to adapt programs for people who are deaf. A potential source for funding to pay for such services are service clubs such as the Knights of Columbus, which has a specific outreach focus for people with cognitive disabilities.

An interviewee suggested that there is a need for computer classes adapted for people with cognitive disabilities, which could include a partner to assist individuals as they attend regular Internet training sessions. Another suggestion was that the library plan family programs of interest for all ages in the evening or on weekends. Parents of children or adults with cognitive disabilities, as well as many adults with cognitive disabilities, work during the day. Adults with cognitive disabilities may also be involved in activities and programs during the day and cannot attend library programs scheduled during weekdays. Attending programs

of general interest for all ages helps adults with cognitive disabilities feel part of the community. These programs could include a magician, musician, or storyteller, but the subject material should be of interest to both children and adults. Parents of children with cognitive disabilities appreciate libraries adapting their story programs to accommodate their children.

Walling and Irwin (1995) report that studies indicate watching television, listening to the radio, and listening to recorded music are the most common leisure-time activities for people with cognitive disabilities. They recommend that library collections include toys that encourage tactile-kinesthetic exploration for parents of children with cognitive disabilities. Adults with these disabilities still often use tactile learning, and materials for them could include jigsaw puzzles and board games, electronic math toys, and video and computer games. Many computer games can be adjusted to play at a slower speed, which might allow people with cognitive disabilities to enjoy them. Other types of materials that may be helpful are models of things like the brain or heart. The American Library Association, Association of Specialized and Cooperative Library Agencies' 1999 *Guidelines for Library Services to People with Mental Retardation* recommends that tactile materials and items that involve more than vision are very helpful, such as book and tape or video combinations.

## Accessible Buildings and Services

As the *Guidelines for Library Services for People with Mental Retardation* (American Library Association, Association of Specialized and Cooperative Library Agencies 1999) points out, elaborate interior decoration and complicated floor plans may be confusing for people with cognitive disabilities, and they may need assistance finding their way around. Adults with cognitive disabilities who can read and understand the numbers of the library classification system may need very little assistance, and the library staff may not even be aware of their disabilities. But a person who cannot read may need assistance finding items of interest. Changing the location of a particular collection such as videos or music CDs may cause some confusion or even distress. Staff can help by walking the person to the new location or by greeting the patrons as they come into the library, telling them there have been some collection location changes, and then showing them the new areas.

### Visual Directory at the Madison Public Library

For about a year the Madison Public Library's central location piloted a visual directory. The primary targeted groups were people who had cognitive or learning disabilities. It also benefited people who lost their ability to read or speak because of a stroke, as well as patrons who had speech problems. It also was helpful for children who could not read well and people who used English as their second language. Patrons who did not want to ask a librarian for assistance also used the directory.

When activated, the directory welcomed the patrons to the library and explained that all questions could be answered at the desk located near the directory. Then the patrons were invited to select an item listed on the directory's index. The items were listed both in print and as a visual image. The display included a floor plan for both levels of the building. The patron could select from a directory that listed such things as videos, music CDs, newspapers, the reference desk, and the children's department, each with a corresponding visual symbol. A voice gave simple directions on how to find the location. The visual symbol was also located in the appropriate place on the building's floor plan.

The product was custom designed by Attainment Company, located in Verona, Wisconsin. Attainment is a pioneer in adapted communication devices and in nonprint methods of delivering information. The company has a strong interest in visual directories in public buildings.



## Marketing

Because many adults with cognitive disabilities may not be able to read, or do not read well, they are not likely to get information about local events from the daily newspapers. Many cannot travel independently, and thus they may not come to the library alone. A frequent recommendation mentioned in the interviews was to target the families and support agencies for people with cognitive disabilities. Libraries might contact the following agencies:

- Regional chapters of The Arc
- Sheltered work-placement agencies or locations
- Faith-based programs with outreach activities for adults who have cognitive disabilities
- High school programs that may serve students until age 21
- Local chapters of United Cerebral Palsy
- Independent living centers

## References: Cognitive Disabilities

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American Library Association, Association of Specialized and Cooperative Library Agencies. 1999. *Guidelines for Library Services for People with Mental Retardation*. Chicago: American Library Association.

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Walling, Linda Lucas, and Marilyn H. Harrenbrock. 1993. *Disabilities, Children, and Libraries: Mainstreaming Services in Public Libraries and School Library Media Centers*. Westport, Conn.: Libraries Unlimited.

Walling, Linda Lucas, and M. M. Irwin. 1995. *Information Services for People with Developmental Disabilities: The Library Manager's Handbook*. Westport, Conn.: Greenwood Press.

Wisconsin Department of Health and Family Services. 2001. *1999–2001 Biennial Report*. Madison: Wisconsin Department of Health and Family Services.

## Additional Resources

### National Organizations

American Association on Mental Retardation. <[www.aamr.org](http://www.aamr.org)>; 800-424-3688 or 202-387-1968; 444 N. Capitol Street NW, Suite 846, Washington, DC 20001-1512. Provides information about the mental retardation and disabilities field.

The Arc of the United States. <[www.thearc.org](http://www.thearc.org)>; 800-433-5255 or 301-565-5451; 1010 Wayne Avenue, Suite 650, Silver Spring, MD 20910. A national organization of and for people with mental retardation and related developmental disabilities and their families.

Developmental Disabilities Leadership Forum. <[www.ddleadership.org](http://www.ddleadership.org)>; 781-642-0001; Eunice Kennedy Shriver Center, 200 Trapelo Road, Waltham, MA 02452-6319. The Forum is a project of the Shriver Center, a division of the University of Massachusetts Medical School, offering courses, discussion groups, articles, and events related to developmental disabilities.

National Down Syndrome Society (NDSS). <[www.ndss.org](http://www.ndss.org)>; 800-221-4602 or 212-460-9330; 666 Broadway, New York, NY 10012. The largest nongovernmental supporter of Down syndrome research in the United States.

National Fetal Alcohol Syndrome (NFAS). <[www.nofas.org](http://www.nofas.org)>; 202-785-4585; 216 G Street NE, Washington, DC 20002. Dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and improving the quality of life for those individuals and families affected by fetal alcohol syndrome.

Special Olympics. <[www.specialolympics.org](http://www.specialolympics.org)>; 800-700-8585; 1325 G Street NW, Suite 500, Washington, DC 20005-3104. Dedicated to empowering individuals with mental retardation to become physically fit, productive, and respected members of society through sports training and competition.

United Cerebral Palsy (UCP). <[www.ucpa.org](http://www.ucpa.org)>; 800-872-5827; 202-776-0406 (TTY); 1660 L Street NW, Suite 700, Washington, DC 20036. Advances the independence, productivity, and full citizenship of people with cerebral palsy and other disabilities through independence, inclusion, and self-determination.

U.S. Department of Health and Human Services, The Administration for Children and Families, Administration on Developmental Disabilities. <[www.acf.dhhs.gov/programs/add/states/ddcouncils.htm](http://www.acf.dhhs.gov/programs/add/states/ddcouncils.htm)>; 202-690-6590; HHH 300-F, 370 L'Enfant Promenade SW, Washington, DC 20447. Ensures that individuals with developmental disabilities and their families have access to services and assistance that promote independence, productivity, and inclusion.

## Wisconsin Organizations

- The Arc–Wisconsin (formerly the Wisconsin Association for Retarded Citizens). <[danenet.danenet.org/arcw/](http://danenet.danenet.org/arcw/)>; 608-251-9272; 121 S. Hancock Street, Madison, WI 53703. Provides advocacy, guardianship services, training, and information and referral services for people with developmental disabilities. Includes county-level chapters and their locations.
- Attainment Company. <[www.attainmentcompany.com](http://www.attainmentcompany.com)>; 608-845-7880; 504 Commerce Parkway, Verona, WI 53593. Creates products and resources for people who have a family member with a disability, including seniors, and for people with developmental and other disabilities.
- Autism Society of Wisconsin (ASW). <[www.asw4autism.org](http://www.asw4autism.org)>; 888-428-8476 or 920-993-0279; 103 W. College Avenue, Suite 709, Appleton, WI 54911-5744. Provides support and information to the autism community and sponsors an annual conference, produces a free quarterly newsletter, maintains a directory, and makes referrals.
- Family Village Community Center. <[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)>; This Web site is maintained by the Waisman Center at the University of Wisconsin–Madison. It integrates information, resources, and communication opportunities for persons with cognitive and other disabilities, for their families, and for professionals who work with them.
- Knights of Columbus, Wisconsin State Chapter. <[www.wikofc.org](http://www.wikofc.org)>; 608-274-5750; 4297 W. Beltline Highway, Madison, WI 53711. A Catholic organization with a special focus on people with cognitive disabilities. Local chapters may be willing to help raise funds for library projects. State organization makes grants between \$3,500 and \$4,500; public libraries are eligible. Contact the Knights of Columbus to get the current name of the chairman of the Committee to Aid State Citizens with Mental Handicaps.
- People First Wisconsin. <[www.peoplefirstwi.org](http://www.peoplefirstwi.org)>; 888-270-5352; 3195 S. Superior Street, Milwaukee, WI 53207. A statewide advocacy organization for people with disabilities to help have their voices heard.
- Trace Research and Development Center, University of Wisconsin–Madison. <[www.trace.wisc.edu](http://www.trace.wisc.edu)>; 608-262-6966; 608-263-5408 (TTY); 5901 Research Park Boulevard, Madison, WI 53719-1252. Works on ways to standardize information technologies and to make telecommunications systems more accessible and usable by people with disabilities.
- United Cerebral Palsy–Wisconsin (UCP Wisconsin). <[www.ucpa.org](http://www.ucpa.org)> (the Web address for all Wisconsin affiliates is the national organization Web page); 800-261-1895 or 715-832-1782; 206 Water Street, Eau Claire, WI 54703. UCP Wisconsin is operated by the Eau Claire chapter.
- UCP of Greater Dane County. 608-273-4434; 1502 Greenway Cross, Madison, WI 53713.
- UCP of Mideast Wisconsin. 800-261-1895 or 920-424-4071; 920-424-4076 (TTY); 36 Broad Street, Suite 120, P.O. Box 1241, Oshkosh, WI 54903-1241.
- UCP of North Central Wisconsin. 800-472-4408 or 715-842-8700; 740 N. Third Street, Wausau, WI 54403.
- UCP of Southeastern Wisconsin. 888-482-7739 or 414-329-4500; 414-329-4511 (TTY); 7519 W. Oklahoma Avenue, Milwaukee, WI 53219.
- UCP of West Central Wisconsin. 715-832-1782; 206 Water Street, Eau Claire, WI 54703.
- Waisman Center, University of Wisconsin–Madison. <[www.waisman.wisc.edu](http://www.waisman.wisc.edu)>; 608-263-5776 or 608-263-5910; 608-263-0802 (TTY); 1500 Highland Avenue, Madison, WI 53705-2280. Dedicated to the advancement of knowledge about human development and developmental disabilities throughout a person's life span. The center is one of nine national centers that encompasses a Mental Retardation Developmental Disabilities Research Center and a Center for Excellence in Developmental Disabilities.
- Wisconsin Council on Developmental Disabilities. <[www.wcdd.org](http://www.wcdd.org)>; 608-266-7826; 608-266-6660 (TTY); 600 Williamson Street, P.O. Box 7851, Madison, WI 53707-7851. Dedicated to improving the independence, productivity, and integration of people with developmental disabilities.
- Wisconsin Department of Health and Family Services. <[www.dhfs.state.wi.us](http://www.dhfs.state.wi.us)>; 608-266-1865; 608-267-7371 (TTY); 1 W. Wilson Street Madison, WI 53702.
- Bureau of Developmental Disabilities Services (BDDS), Division of Supportive Living. <[www.dhfs.state.wi.us/bdds](http://www.dhfs.state.wi.us/bdds)>. Responsible for services and supports for people with developmental disabilities in terms of independent living and preventing placement in institutions.
- Centers for People with Developmental Disabilities. <[www.dhfs.state.wi.us/Disabilities/dd\\_ctr/DDcenters.htm](http://www.dhfs.state.wi.us/Disabilities/dd_ctr/DDcenters.htm)>. The Division of Care and Treatment Facilities operates three centers for people with developmental disabilities in Wisconsin—Central, Northern, and Southern Centers. Centers are licensed as ICF/MR (intermediate-care facilities for the mentally retarded) facilities and are located in Madison, Chippewa Falls, and Union Grove.
- Community Integration Program (CIP). <[www.dhfs.state.wi.us/bdds/cip.htm](http://www.dhfs.state.wi.us/bdds/cip.htm)>. Helps people with developmental disabilities relocate from state centers and nursing homes back to their communities. Also helps pay for adaptive aids, communication aids, day care, respite care, supportive home care, placement in group homes, supportive employment services, and specialized transportation.
- Self-Determination Project. <[www.dhfs.state.wi.us/bdds/cip.htm](http://www.dhfs.state.wi.us/bdds/cip.htm)>. A grant is used to enhance efforts to involve people with developmental disabilities in decisions regarding what services they receive, where they live, and how they find employment. Dane, La Crosse, and Winnebago Counties were the test sites.

Supported Employment. <[www.dhfs.state.wi.us/bdds/supempl.htm](http://www.dhfs.state.wi.us/bdds/supempl.htm)>. Employment service for individuals with disabilities. Provides ongoing support services, job matching, on-the-job training, and mentoring, as well as assistance with transportation and community living.

Supported Housing. <[www.dhfs.state.wi.us/bdds/housing.htm](http://www.dhfs.state.wi.us/bdds/housing.htm)>. Provides specialized housing counseling and explores housing dilemmas and solutions. The supported-housing specialist also provides consultation to local lenders, property developers, real estate agents, and others involved with housing.

Wisconsin Department of Public Instruction, Educational, Special Education, Cognitive Disabilities. <[www.dpi.state.wi.us/dpi/dlsea/een/cd.html](http://www.dpi.state.wi.us/dpi/dlsea/een/cd.html)>; 608-266-1785; 125 S. Webster Street, P.O. Box 7841, Madison, WI 53707-7841. A consultant in the area of cognitive disabilities working with both parents and teachers to meet the needs of students who have cognitive disabilities.

All Web sites listed in this section were accessed in November 2002.



## Getting Started with Little Money and Time: Cognitive Disabilities

The following are some ideas for public libraries to use when designing services for people with cognitive disabilities.

### BREAKING DOWN BARRIERS

- Greet every patron who walks in the door and offer to assist them if they need help; if appropriate, greet the patrons by their first or last name.

### PLANNING AND COLLABORATION

- Identify the agencies in the community that may be involved with services to people who have cognitive disabilities.
- Get free informational brochures on cognitive disabilities from organizations such as The Arc, Special Olympics, and United Cerebral Palsy. Put this literature into a vertical file or out for the public to pick up as they browse.
- Evaluate the library's adult programming to see if a program could be of interest to adults with cognitive disabilities. Discuss with agency staff ways the program could be adapted if necessary. Ask to try a joint effort on a pilot program to see if the clients attend and enjoy the program.
- If there are routine simple tasks that might make a good volunteer project for adults with cognitive disabilities, invite an agency to work with the library to set up a volunteer project.
- Ask the local Council of the Knights of Columbus if it will fund a subscription to a periodical that includes information on working with adults who have cognitive disabilities, such as *Exceptional Parent* magazine.

### STAFF TRAINING

- Ask service agencies if they could provide a free brief staff and trustee training session for the library.

### COLLECTIONS AND SERVICES

- Assess your collection and identify tactile items that may be of interest to adults with cognitive disabilities. Put them in a highly accessible and visible location during the next visit by a group of patrons who have cognitive disabilities.
- Weed your collection of dated material on the subject of cognitive disabilities, and save reviews of new materials in print and nonprint format for future purchase.

### ACCESSIBLE BUILDINGS AND SERVICES

- Spend some time playing with computer games the library owns that are of interest to all ages. See if they can be adjusted to allow for a longer response time. The next time a group of adults with cognitive disabilities visits the library, invite them to try out the game at a slower speed.
- If groups of adults with cognitive disabilities come regularly to the library and enjoy computers, look into pairing them with high school students who can help answer questions. Many high school students need to perform community service as a graduation requirement, and many student organizations are willing to help out in the community.

### MARKETING

- Put up posters that feature people with cognitive disabilities in positive ways or interacting with the general community.

- Plan a display on the local Special Olympic winners or an art display from the high school classes for students with cognitive disabilities or from a local agency that provides art recreation services for adults with cognitive disabilities.
- Plan displays for Mental Retardation Awareness Month ([www.thearc.org](http://www.thearc.org)) and National Autism Awareness Month ([www.autism-society.org](http://www.autism-society.org)), both in March.

All Web pages listed here were accessed in November 2002.